Case Presentation

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T.T.

T.T. is a 51 year old male with a history of von Hippel-Lindau disease and hemangioblastoma.

His family consists of four sisters.

Advance Directive Status

■ T.T.'s 4 sisters are involved significantly in his medical care.

 T.T. does not have an advance directive.

NIH Admission

 T.T. is admitted to the NIH Clinical Center with worsening balance when walking.

 He also has been experiencing bowel and bladder difficulties.

Initial Workup

MRI at admission shows a large mass on the spine consistent with hemangioblastoma.

 T.T. undergoes a spinal angiogram and embolization procedure.

Mental Decline

 Rupture of a blood vessel leads to bleeding into T.T.'s brain.

 T.T. experiences an acute decline in mental status.

ICU Admission

 T.T. is admitted to the intensive care unit where a ventriculostomy is placed.

 T.T.'s mental status improves over the next 4 days.

Decline

 On day 5, T.T. experiences acute mental status changes.

■ A cerebral angiogram is performed.

Further Decline

 T.T. has significant vasospasm, and a blood vessel ruptures.

He is minimally responsive, with fixed and dilated pupils.

Needlestick

While taking care of T.T., a hospital worker suffers a needlestick injury.

Hospital policy is to perform HIV and hepatitis testing on patients when staff experience accidental sticks.

Sisters' Request

 Because T.T. is unresponsive, consent for the HIV and hepatitis testing are obtained from his sisters.

 His sisters consent, but demand to know the results of the tests.

Question

How should NIH staff respond to the sisters' request to be informed of T.T.'s HIV and hepatitis results?

NIH Policy on HIV Testing M89-1 (rev.)

"If the patient is unable to consent, the most appropriate surrogate decision maker should be approached for permission (e.g. the next of kin or an authorized representative of the patient)."

NIH Policy on HIV Testing M89-1 (rev.)

"The informed consent of the patient before testing for HIV antibodies is required in all cases except for occupational exposure of a health care worker. In these cases, all reasonable attempts should be made to obtain the informed consent of the patient before HIV testing of the blood. However, if the consent is not obtainable, it is justifiable to proceed with the test."